

NEUROSCIENCES, REHABILITATION & VISION

Contact

Leadership team

neurorehabvision.scn@ahs.ca

Key Partners

Alberta Multiple Sclerosis Network

Campus Alberta Neuroscience

Eye Institute of Alberta (University of Alberta)

Faculty of Rehabilitation Sciences (University of Alberta)

Hotchkiss Brain Institute (University of Calgary)

Neuroscience & Mental Health Institute (University of Alberta)

Parkinson's Association of Alberta

Praxis Spinal Cord Injury Institute

Spinal Cord Injury Alberta

<u>Vision Loss Rehabilitation</u> Canada

"With the KQI work, for myself and for Audrey, it is very important to have our voices heard along with the professionals, whether it is optometrists or ophthalmologists. When everything comes down to it, we have the lived experience. Everybody's voice is heard, and everybody's opinion is respected."

Henry Tonkin, Patient Advisor

Major initiatives and achievements, 2022-2023

This year, the Neurosciences, Rehabilitation & Vision (NRV) SCN and its Scientific Office supported collaborative, provincial research to advance system-level quality improvement, evaluation, planning, and change implementation in NRV settings.

Understanding the current state of Long COVID care in Alberta

In October 2022, Drs. Jacqueline Krysa, Kiran Pohar Manhas, Elisavet Papathanassoglou, Chester Ho, and myriad collaborators shared the final report of a 1.5-year evaluation that sought to explore and better understand (a) the experience of COVID-19 recovery in Alberta; (b) factors affecting Long COVID care provision; and (c) factors influencing awareness and adoption of a provincial Long COVID rehabilitation response framework. This pragmatic evaluation used mixed methods to capture patient experiences

(n=390 telephone surveys; n=56 patient interviews); provider perceptions (n=31 early-adopter provider interviews); and provincial health service utilization. Perspectives were gathered from across AHS' five Zones.

Self-reported patient experience indicates that 49% of hospitalized COVID-19 patients experienced Long COVID symptoms as well as 25% of non-hospitalized COVID-19 patients. Also, 31% of hospitalized patients were unable to return to full-time work up to 11 months after acute infection. Convergent analysis identified three key learnings:



- The experience of COVID-19 recovery was marred by challenges in managing chronic symptoms, returning to work, and finding appropriate resources.
- 2. Factors affecting Long COVID care provision related to provider education, patient and provider awareness, as well as the location and accessibility of Long COVID services.
- 3. Barriers to framework adoption related to managing a novel condition, competing clinical priorities, and adaptability of provincial long COVID rehabilitation pathways.

This research is part of seminal learning to equip Alberta Health Services with knowledge to recognize and respond to the evolving needs of persons with Long COVID. This work has been shared with local and provincial stakeholders through presentations, a final report and infographic. Five manuscripts are in preparation (or submitted) for peer-review. Two of these have since been published, in Spring 2023 and Summer 2023. [Note: Links are provided here for convenience; however, these publications are excluded from metrics for this fiscal year as they were published since March 31, 2023.]

Co-designing provincial core sets of key quality indicators (KQI) for neurosurgery, vision, and inpatient rehabilitation

"You can only manage what you measure." It's a familiar tenet in business and other sectors, and identifying and measuring KQIs is also an important part of improving health outcomes and health service delivery. For the NRV SCN, developing an evaluation system for each clinical stream is a fundamental strategic priority identified in its 2023-2027 Transformational Roadmap.

To this end, the Scientific Office has convened and supported three stream-focused provincial steering committees to co-design a modified e-Delphi, consensus-building process to identify priority KQIs. These multidisciplinary steering committees included patient and family advisors, physicians, nurses, allied health professionals, community representatives, operational leaders, and division leads from across the province, with clinical co-chairs and the NRV SCN Scientific Office providing tactical and research support. Between March 2022 and April 2023, stakeholders co-designed:

Neurosurgery: 42 potential KQIs for adult, inpatient neurosurgical care. The process prioritized **12 KQIs** related to four key measures: **infections**; **surgical complications**; **safe**, **effective & efficient care**; **and high-quality communication**.

Vision: 27 potential KQIs for the care of patients with cataract or glaucoma in Alberta. The process prioritized **13 KQIs** by 33 e-Delphi participants, related to the measurement of three quality dimensions: **acceptability, accessibility, and safety**.

Inpatient Rehabilitation: 56 potential KQIs for inpatient rehabilitation units in Alberta (as well as 25 supplemental KQIs for Older Adult or Pediatric populations). Current recruitment identified 100+ provincial stakeholders interested in participating in the modified e-Delphi process.

This evidence-based process has advanced stakeholder engagement in the identification, evaluation, development, and implementation of appropriate KQIs provincially. Next steps include co-development of technical definitions; planning operationalization and implementation; and enacting a multi-modal communication strategy to disseminate results.

Advancing research & building capacity in Alberta

Multiple Sclerosis, Parkinson's Disease and quality of care in Alberta



In June 2022, the Scientific Office hosted the 2022 NRV SCN Research Planning Summit, where patients, community partners, researchers, and clinicians (n=29) from across the province convened to identify challenges to multiple sclerosis (MS) and Parkinson's Disease (PD) care provision in Alberta. Identified gaps related to access, human resources, and system navigation. Current care challenges related to equity, access, long-term management, and preservation of function in MS and PD.

This summit led to a focused funding call: the 2023 Research Grant Competition on MS or PD. This funding call aims to support health services or policy research that creates momentum and advances quality of care for persons with MS, PD (or both) in Alberta. The successful applicants, Dr. Davide Martino and his team, will use this funding to leverage Connect Care and a co-designed educational curriculum to improve the quality of inpatient PD care for people in Alberta.

Impacts on health and care

The NRV SCN continues to build relationships with patients, families, research institutes, academics, clinicians, and operational partners to leverage available resources and expertise. Together, they actively collaborate to:

- Co-design care transformation through evidence
- Harness innovation to drive care excellence across the continuum
- Enhance equitable access to quality care for all in Alberta

What's next: Actions and areas of focus

- Address gaps and variations in care, and barriers to equitable access
- Develop an evaluation system for neurosciences, rehabilitation and vision care
- Build clinical pathways and service delivery
- Identify and integrate virtual health into service delivery

NEUROSCIENCES, REHABILITATION AND VISION

Grants and Publications

Engagement

Outcomes and Impact



22

Peer-reviewed Publications



29

Workshops & Presentations

Facilitated Alberta's involvement in a national Long COVID research network that received \$19.99M in CIHR funding



\$21.5M

Research Grants



191

Research Members

Started translating the KQI results into tangible data dashboards & outputs to promote a Learning Health System approach to neurosurgery, vision, and inpatient rehabilitation

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